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Experiences of People living with Diagnosis of Esophageal Cancer: Case of Eastern Cape Municipalities, South Africa: A Phenomenological Study

Experiences of People living with Diagnosis of Esophageal Cancer: Case of Eastern Cape Municipalities, South Africa: A Phenomenological Study

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Abstract
Esophageal cancer is a major health issue in South Africa, especially in rural areas of the Eastern Cape, which has the highest incidence rates. While risk factors are well studied, there is limited research on patients' lived experiences of diagnosis, treatment, and survival. This study explored the lived experiences of individuals diagnosed with esophageal cancer in Eastern Cape municipalities, examining their diagnostic journeys, coping mechanisms through treatment, and perceptions of existing support structures. A qualitative phenomenological design was employed; 12 participants (9 females, three males) aged 47-59 years were purposively sampled from three hospitals in Buffalo City, O.R. Tambo, and Amathole municipalities. In-depth semi-structured interviews were used. Data was analysed using Braun and Clarke's thematic analysis, guided by the Health Belief Model and Health Promotion Model. Three major themes emerged: (1) Delayed diagnosis due to late help-seeking, use of traditional healing, severe symptoms including dysphagia, haemoptysis, and weight loss; (2) Coping through treatment involving chemotherapy and radiation therapy with substantial side effects and financial burden; (3) Reliance on family support alongside gaps in health education, access to cancer services, and financial help for proper nutrition. The findings show that managing esophageal cancer in rural South Africa involves a mix of medical, traditional, and family care. They highlight the need for better community education on early symptoms, improved access to treatment facilities, emotional, and financial support for patients. The study recommends healthcare policies that are patient-centred, respect cultural practices and ensure access to proper medical treatment.

Introduction

Esophageal cancer is the 11th most common cancer worldwide (2022), with over 511,000 new cases and a high mortality rate, particularly affecting men. The disease presents two primary histological subtypes: squamous cell carcinoma, predominantly affecting the upper two-thirds of the esophagus, and adenocarcinoma, typically manifesting in the lower third at the gastroesophageal junction. With a five-year survival rate between 15% and 25%, esophageal cancer carries an exceptionally poor prognosis, particularly when diagnosed at advanced stages (Smyth et al., 2017).

Esophageal cancer continues to pose a major global public health challenge, affecting not only patients medically but also creating serious social and economic burdens. The disease significantly reduces quality of life and places considerable pressure on healthcare systems, while also impacting broader economic development. As populations change and lifestyles evolve, patterns of prevalence, incidence, and mortality are becoming increasingly complex and variable, highlighting the need for a deeper and more comprehensive understanding of the disease (Liu, et, al, 2025). While adenocarcinoma predominates in Western countries, squamous cell carcinoma constitutes the majority of cases in developing regions, including South Africa (Sun,et al,2023). These disparities reflect complex interactions between environmental risk factors, dietary patterns, infectious agents, and access to healthcare services.

Within South Africa, the Eastern Cape Province demonstrates the highest esophageal cancer incidence rates nationally, particularly concentrated in rural areas such as the former Transkei region. Epidemiological investigations dating back to the 1950s identified this region as a high-risk area, with incidence rates of squamous cell carcinoma reaching 46.7 per 100,000 for men and 19.2 per 100,000 for women (Plunders et al., 2017). These rates substantially exceed national and global averages, establishing esophageal cancer as the leading cause of cancer-related mortality in the region.

Multiple risk factors contribute to the elevated esophageal cancer burden in the Eastern Cape. Consumption of maize contaminated with *Fusarium verticillioides*, a mycotoxin-producing fungus, represents a significant environmental exposure in rural communities where maize constitutes a dietary staple. Additional risk factors include tobacco smoking, alcohol consumption, gastroesophageal reflux disease, obesity, and habitual consumption of extremely hot beverages (Liu et al., 2024). Socioeconomic factors, including poverty, limited health literacy, and geographic barriers to healthcare access, further compound disease burden through delayed diagnosis and treatment initiation.

Despite substantial epidemiological research documenting esophageal cancer incidence, risk factors, and survival outcomes in the Eastern Cape, significant gaps persist in understanding patient experiences and perspectives. The existing literature predominantly adopts biomedical frameworks, emphasising clinical presentation, diagnostic procedures, and treatment modalities while marginalising individuals' subjective experiences. This research gap is particularly problematic in rural South African contexts, where healthcare systems, cultural health beliefs, and socioeconomic constraints intersect to shape illness experiences that are not captured by conventional epidemiological approaches.

Current qualitative research on cancer experiences in South Africa disproportionately focuses on breast and cervical cancers, leaving esophageal cancer patients' voices largely unheard in academic and policy discourse. Studies conducted in Ethiopian contexts reveal that cancer patients frequently possess limited disease knowledge and harbour negative perceptions regarding treatment effectiveness (Asefa et al., 2025). Healthcare providers often fail to elicit patients' narratives during clinical encounters, resulting in care that fails to address patients' actual experiences, concerns, and support needs (Wang et al., 2023).

Furthermore, esophageal cancer patients confront distinctive challenges related to disease symptomatology, including severe dysphagia, nutritional compromise, and rapid physical deterioration. These experiences profoundly impact patients' quality of life, family dynamics, financial stability, and emotional well-being. Understanding these lived experiences proves essential for developing patient-centred interventions, improving healthcare delivery, and informing policy initiatives aimed at reducing esophageal cancer morbidity and mortality in high-burden regions.

This study aimed to explore the lived experiences of people diagnosed with esophageal cancer in Eastern Cape municipalities.

Theoretical Framework

This study employed dual theoretical frameworks, the Health Belief Model (HBM) and the Health Promotion Model (HPM), to examine health behaviours and experiences among patients with esophageal cancer. These complementary frameworks provided conceptual lenses for interpreting participants' health-seeking behaviours, treatment adherence, and perceptions of disease risk and severity.

Health Belief Model

The Health Belief Model, developed by United States public health researchers in the 1950s, posits that health behaviours are influenced by individuals' perceptions of disease susceptibility, severity, benefits of preventive action, and barriers to such action (Rosenstock, 1966). The model comprises six core constructs: perceived susceptibility (beliefs about likelihood of developing a health condition), perceived severity (beliefs about seriousness of a condition and its consequences), perceived benefits (beliefs about effectiveness of preventive actions), perceived barriers (beliefs about costs or obstacles to acting), cues to action (factors triggering health behaviours), and self-efficacy (confidence in ability to successfully execute health behaviours).

In the context of esophageal cancer, the HBM helped interpret why participants delayed seeking medical care despite experiencing severe symptoms. Perceived barriers, including geographic distance to healthcare facilities, financial constraints, fear of diagnosis, and cultural preferences for traditional healing, often outweighed perceived benefits of early medical consultation. Understanding these perceptions proved crucial for developing recommendations to improve early detection and treatment initiation.

However, the HBM possesses acknowledged limitations. It emphasises individual cognitive factors while underestimating social, environmental, and structural influences on health behaviours. The model inadequately addresses how socioeconomic constraints, such as poverty and food insecurity, limit individuals' capacity to engage in health-promoting behaviours regardless of their beliefs. Additionally, the HBM overlooks habitual behaviours and social approval as motivators for health actions (Rosenstock, 1974).

Health Promotion Model

Pender's Health Promotion Model, developed in 1982 and subsequently revised, provides a broader framework incorporating individual characteristics, behaviour-specific cognitions, and environmental influences on health-promoting behaviours (Pender, 2011). Unlike disease-prevention models, the HPM focuses on factors that motivate individuals toward positive health outcomes and well-being. The model recognises humans as biopsychosocial beings shaped by environmental contexts while actively creating conditions supporting optimal health potential.

Applied to this study, the HPM illuminated how participants navigated treatment decisions, adhered to therapeutic regimens despite significant side effects, and mobilised family and community support systems. The framework acknowledged the complex interplay between individual agency and structural constraints in shaping health behaviours among patients with esophageal cancer. By integrating both HBM and HPM perspectives, the study achieved a comprehensive understanding of participants' experiences encompassing both disease-prevention behaviours and health promotion strategies throughout their cancer journeys.

Methods

Research Design

This study employed a qualitative phenomenological research design to explore the lived experiences of individuals diagnosed with esophageal cancer. Phenomenology, as a philosophical and methodological approach, focuses on understanding the essence and meaning of human experiences as individuals perceive them (Cypress, et al., 2018). This approach proved particularly appropriate for investigating subjective experiences of illness, suffering, treatment, and survival among esophageal cancer patients.

The phenomenological approach prioritises participants' perspectives without imposing predetermined hypotheses or theoretical assumptions on the data. This methodology employs a range of data collection methods, including in-depth interviews, focus groups, participant observation, and analysis of personal narratives. For this study, in-depth semi-structured interviews constituted the primary data collection method, enabling participants to articulate their experiences in detail while allowing the researcher to probe emergent themes.

Study Setting

The study was conducted in the Eastern Cape Province, located in southeastern South Africa. The province comprises six district municipalities (Amathole, Chris Hani, Joe Gqabi, Sarah Baartman, O.R. Tambo, and Alfred Nzo) and two metropolitan municipalities (Nelson Mandela Bay and Buffalo City). Research sites included three municipalities selected to represent different geographic and demographic contexts within the province.

Participants were recruited from three hospitals: Frere Hospital in Buffalo City Metropolitan Municipality, Mthatha General Hospital (Nelson Mandela Academic Hospital) in O.R. Tambo District Municipality, and Butterworth Hospital in Amathole District Municipality. These facilities serve as primary oncology referral centres for their respective regions, providing chemotherapy and radiation therapy services to esophageal cancer patients from surrounding rural communities.

Sampling Strategy and Participants

Purposive sampling, a nonprobability sampling technique, was employed to recruit participants who met specific inclusion criteria. This approach enabled intentional selection of information-rich cases capable of providing in-depth insights into the phenomenon under investigation (Bless et al., 2013). Inclusion criteria specified individuals diagnosed with esophageal cancer who were currently receiving or had completed treatment at one of the three study hospitals.

The final sample comprised 12 participants, including nine females and three males, aged 47 to 59 years. All participants self-identified as Black South Africans. Distribution across study sites included seven participants from Frere Hospital (Buffalo City), 3 from Mthatha General Hospital (O.R. Tambo), and two from Butterworth Hospital (Amathole). This sample size aligns with recommendations for phenomenological research, which typically involves 6 to 12 participants to achieve data saturation while maintaining manageable depth for analysis.

Participants' educational backgrounds ranged from primary school completion to high school, and monthly household incomes ranged from R1,300 to R7,500 (approximately USD 70-400). Duration since diagnosis ranged from 1 month to 5 years, providing diversity in disease progression and treatment experiences.

Data Collection

Data collection occurred over a three-week period, in 2023 with one week allocated to each municipality. In-depth semi-structured interviews served as the primary data collection method.

This approach combined predetermined open-ended questions aligned with research objectives while maintaining flexibility to explore emergent themes and follow participants' narratives (Bless et al., 2013).

Interview questions explored several domains: symptom recognition and initial responses; pathways to diagnosis, including traditional and biomedical healthcare utilisation; experiences with diagnostic procedures and communication of diagnosis; treatment experiences, including side effects and adherence challenges; psychosocial impacts on participants and families; coping strategies and resilience factors; and perceptions of support systems and unmet needs. Interviews ranged from 45 to 90 minutes in duration and were conducted in participants' preferred language (isiXhosa or English), with translation provided when necessary.

Interviews were audio-recorded with participants' consent and subsequently transcribed verbatim. Field notes documenting non-verbal communications, contextual observations, and researcher reflections complemented interview transcripts. Data collection continued until thematic saturation was achieved, as evidenced by the absence of new themes emerging from successive interviews.

Data Analysis

Thematic analysis (Ahmed, et al., 2025) six-phase framework guided data analysis. This flexible method involves systematically identifying, analysing, and reporting patterns (themes) within qualitative data. The approach does not require adherence to specific theoretical orientations, making it accessible and widely applicable across disciplines.

The analysis process proceeded through six phases: (1) familiarisation with data through repeated reading of transcripts and immersion in content; (2) generating initial codes through systematic identification of interesting features across the dataset; (3) searching for themes by collating codes into potential overarching themes; (4) reviewing themes to ensure coherence within themes and distinction between themes; (5) defining and naming themes to capture their essence; and (6) producing the report with vivid examples and analytical narrative relating findings to research questions and literature.

Coding was conducted manually, with the researcher maintaining a coding framework documenting codes, definitions, and exemplar quotations. Thematic development involved iterative refinement, with preliminary themes presented to supervisory team members for critical review and consensus validation. This collaborative approach enhanced analytical rigour and credibility of findings.

Ethical Considerations

The study adhered to Walter Sisulu University's research ethics requirements and received institutional ethics clearance with protocol number (REC/1(IV) 2024) prior to data collection. Ethical principles of autonomy, beneficence, non-maleficence, and justice guided all research activities.

Informed consent was obtained from all participants following a comprehensive explanation of the study's purpose, procedures, potential risks and benefits, the voluntary nature of participation, and the right to withdraw at any time without consequences. Consent forms were provided in participants' preferred language. For participants with limited literacy, consent procedures involved verbal explanation with witness documentation.

Confidentiality and anonymity were maintained throughout the research process. Participants were assigned numerical identifiers, and all personally identifying information was removed from transcripts. Audio recordings and transcripts were stored securely with access limited to the research team. This manuscript presents participant quotations using numerical identifiers (e.g., Respondent 1, Respondent 2) to protect anonymity.

Given the sensitive nature of discussing cancer experiences, provisions were made for emotional support during and following interviews. Participants exhibiting distress were offered referral to hospital social work and counselling services. No adverse events occurred during data collection, and several participants expressed appreciation for the opportunity to share their experiences.

Results

Thematic analysis of interview data yielded three major themes corresponding to the study's research objectives: (1) Experiences of Living with Esophageal Cancer, (2) Coping Mechanisms through Treatment, and (3) Support Structures and Unmet Needs. Each theme encompassed multiple sub-themes reflecting the complexity and diversity of participants' experiences.

Theme One: Experiences of Living with Esophageal Cancer

Symptom Recognition and Initial Responses

Participants described experiencing multiple debilitating symptoms prior to diagnosis, with dysphagia (difficulty swallowing) emerging as the most commonly reported and distressing symptom. Other frequently mentioned symptoms included persistent coughing with haemoptysis (coughing blood), severe heartburn, unintentional weight loss, chronic fatigue, hoarseness, constipation, and stomach cramps. These symptoms significantly impaired participants' ability to maintain nutrition, perform daily activities, and sustain employment.

Respondent 1 described the progression of symptoms: "I had loss of appetite, every time I tried to eat, I would vomit, I never felt any pain in my body. I lost energy. It is not easy having this type of esophageal cancer, you watch people eating at times you want to also eat, but you cannot." This quotation illustrates the profound impact of dysphagia on nutritional intake and the psychological distress of being unable to participate in the social activity of shared meals.

Respondent 4 elaborated on swallowing difficulties: "I had difficulties in swallowing food, especially the solid food; as a result, I didn't eat, as it was painful to swallow. My voice was hoarse; it would be like I had been singing for the whole night in the cold. Also, I had to clear my throat every time, which was very irritating and distracting. I'm always having back pain and energy loss."

Haemoptysis provoked particular alarm among participants. Respondent 6 recounted:

"It started like a normal cough, but I noticed that when I'm coughing, blood comes out of my mouth, and it was a very painful cough." The presence of blood in sputum served as a critical "cue to action" in the Health Belief Model, prompting several participants to seek medical evaluation despite prior delays.

Delayed Help-Seeking and Traditional Healing

A striking pattern across participant narratives involved significant delays between symptom onset and biomedical healthcare consultation. These delays, ranging from weeks to months, reflected complex interactions between perceived barriers to medical care, reliance on traditional healing systems, and insufficient awareness of esophageal cancer symptoms as medical emergencies.

Several participants initially attributed symptoms to less serious conditions or spiritual causes, leading them to seek traditional healing. Respondent 8 explained:

"I lost weight and visited traditional healers because I believed that it was something traditional medicine could fix; little did I know that it was developing every day. As a traditional man, I believed that nothing traditional medicine could not fix, so it was hard for me to accept that I needed medical attention from the hospital."

Respondent 9, a traditional healer herself, described the conflict between professional identity and health needs:

"As a traditional healer, it was not easy for me to just decide to visit the hospital for medical attention. I am used to healing people, but because I was taking care of my sisters who also had esophageal cancer before me, it made me reconsider traditional healing and consider visiting the hospital. It is still not comfortable going to the hospital because people will be asking, why can't you heal yourself or You have lost the healing powers."

These narratives reveal how cultural health beliefs and professional identities intersect to influence health-seeking behaviours. The perceived incompatibility between traditional and biomedical healing systems created barriers to timely care, particularly for individuals holding respected positions within traditional healing practices.

Additional barriers to help-seeking included fear of a diagnosis, a desire to avoid worrying family members, and the hope that symptoms would resolve spontaneously. Respondent 8 noted: "I hid from my family that I was sick until it was too late; esophageal cancer was found at a later stage. I was hiding this from my family because I thought the symptoms would eventually go away, and I didn't want to worry them." Such concealment resulted in progression to advanced disease stages before treatment initiation.

Psychosocial and Economic Impacts

Beyond physical symptoms, esophageal cancer diagnosis and treatment imposed substantial psychosocial and economic burdens on participants and their families. Emotional responses included shock, fear, anxiety, depression, and anticipatory grief. Several participants described feeling like burdens to their families due to increased dependency for activities of daily living and caregiving requirements.

Respondent 1 articulated these feelings:

"As for the people taking care of you, it is not easy for them, and also it feels like you are a burden because they have to cancel their day-to-day social life so that they can take care of you." This quotation reflects participants' acute awareness of the sacrifices family caregivers make, which contribute to psychological distress beyond the disease itself.

Financial hardship constituted another pervasive theme. Treatment requirements, including frequent hospital visits for chemotherapy and radiation therapy, imposed high costs for transportation, medications, and nutritional supplements. Respondent 3 explained:

"You need to change your lifestyle, which is a bit expensive. Eating healthy foods all the time requires financial support. For me, it was rather difficult as I am not getting a stable and good income."

Many participants relied on small government grants or sporadic informal employment, with monthly household incomes insufficient to meet both basic needs and cancer-related expenses. This financial strain compounded existing vulnerabilities and constrained participants' capacity to adhere to recommended dietary modifications and treatment regimens.

Theme Two: Coping Mechanisms through Treatment

Chemotherapy Experiences and Side Effects

All participants received chemotherapy as part of their cancer treatment regimen, with several receiving combined chemotherapy and radiation therapy. While participants recognised chemotherapy as essential for disease control, they described significant treatment-related side effects that profoundly impacted quality of life. Commonly reported chemotherapy side effects included severe nausea and vomiting, debilitating fatigue, alopecia (hair loss), mucositis (mouth sores), peripheral neuropathy (numbness and tingling), and myelosuppression manifesting as increased infection susceptibility.

Respondent 2 described the chemotherapy experience:

"I am receiving treatment from a medical doctor for esophageal cancer, which is chemotherapy; it has its effects, which are nausea, fatigue, hair loss, tiredness, and headaches. Chemotherapy is very painful. It gets better with time, but at the first stage of receiving the treatment, the side effects are extreme; one would swear it's the end of their world."

Hair loss emerged as particularly distressing for female participants due to its visible nature and associated social stigma. Respondent 6 elaborated:

"For chemotherapy treatment, I lost my hair and had to cut the remaining pieces of hair. This resulted in me having to wear hair wigs every day." This adaptation strategy, wearing wigs, represents one coping mechanism participants employed to manage treatment side effects and maintain social identity.

Despite these challenges, participants demonstrated remarkable resilience and adherence to treatment. The hope for disease remission and survival, coupled with family support, motivated continued chemotherapy engagement even when side effects proved nearly intolerable. Respondent 10 reflected: "Although it is a very stressful thing to have this type of illness, I keep telling myself that I will get better, thinking of my family, as they are the ones who keep me going."

Radiation Therapy Experiences

Participants receiving radiation therapy reported distinct side effect profiles compared to chemotherapy, including severe esophagitis (inflammation of the esophagus), skin changes at radiation sites, chronic fatigue, and diarrhoea. Respondent 5 noted:

"I am getting treatment from the medical doctor; I am receiving chemotherapy and radiation therapy treatment. I suffer from fatigue, exhaustion, skin dryness, and headaches each and whenever I go for treatment."

Radiation-induced esophagitis exacerbated pre-existing dysphagia, creating a vicious cycle where treatment designed to shrink tumours temporarily worsened swallowing difficulties. Participants managed this challenge by making dietary modifications, primarily by consuming soft foods and nutritional supplements. However, the requirement for specialised nutritional products imposed additional financial burdens.

Some participants combined biomedical and traditional treatments. Respondent 8 explained:

"At first, I was getting treatment from a traditional healer, and I still use some of his traditional medicine together with chemotherapy and radiation therapy. I am experiencing fatigue, diarrhoea, and vomiting every session of treatment." This integrative approach reflects medical pluralism in South African healthcare contexts, where patients navigate multiple healing systems simultaneously.

Geographic Barriers to Treatment Access

Participants universally identified geographic barriers as significant obstacles to treatment adherence. Oncology services, including chemotherapy and radiation therapy facilities, are centralised in tertiary hospitals located in urban centres. Many participants resided in rural communities, requiring several hours of travel to reach treatment facilities.

Respondent 11 articulated this challenge: "Access to treatment should be available for all; the thing of having to travel for hours to get to the hospital is not assisting and is not doing justice at all." Travel requirements imposed financial costs for transportation, time costs affecting employment, and physical exhaustion for patients already debilitated by disease and treatment.

These geographic barriers occasionally resulted in missed appointments or treatment delays, potentially compromising treatment effectiveness. Family members often needed to accompany patients to provide transportation and emotional support, further straining household resources and family dynamics.

Theme Three: Support Structures and Unmet Needs

Family Support as Primary Resource

Family emerged overwhelmingly as the primary support structure for esophageal cancer patients. All participants described relying heavily on family members for instrumental support (transportation, meal preparation, medication management, financial assistance) and emotional support (companionship, encouragement, hope). For many participants, family support proved essential for survival and for completing treatment.

Respondent 11 expressed gratitude: "I have my family, who takes care of me; it's not easy, but they are with me every step of my healing journey.

"Respondent 4 elaborated: "I have the best care one could ever ask for; my family has been there from day one. The medical staff is so patient with me; it's very disturbing to have to deal with an adult who cannot do things for themselves, but it is a different story for them. I appreciate my family and the medical staff."

Family caregiving often requires substantial sacrifices. Respondent 12 noted:

"After diagnosis, my sister had to come and stay with me so that she could take me to the hospital when needed to do so and also to make sure that I was well taken care of. It was and is still emotionally draining to see my loved ones having to quit their day-to-day life to be with me."

These narratives highlight the dual-edged nature of family support: while essential and deeply appreciated, it also generated guilt and emotional distress for patients who recognised the burdens imposed on family members. This finding underscores the need for support services addressing both patient and caregiver well-being.

Gaps in Health Education and Awareness

Participants consistently identified inadequate public health education about esophageal cancer as a critical gap. Many participants possessed limited awareness of esophageal cancer prior to diagnosis, contributing to delayed help-seeking and late-stage presentation. This knowledge deficit extended to families and communities, resulting in insufficient social support and occasional stigmatisation.

Respondent 11 emphasised: "I didn't know about esophageal cancer until I was diagnosed with it, it is important to do education on esophageal cancer. "Respondent 10 concurred: "Health education on esophageal cancer is needed in our communities because people tend not to pay attention to the symptoms until it's too late."

Participants recommended community-based health education campaigns utilising multiple channels, including radio broadcasts, community health worker outreach, and traditional leader engagement. Education content should emphasise warning symptoms requiring urgent medical evaluation, risk-reduction strategies, and the availability of treatment services.

Respondent 4 suggested:

"Health awareness is very important so that whenever a person experiences a certain and unusual symptom, they can seek medical attention straight away." Such preventive education aligns with both the Health Belief Model (increasing perceived susceptibility and severity) and the Health Promotion Model (enhancing health literacy and self-efficacy) frameworks.

Financial and Nutritional Support Needs

Participants articulated urgent needs for financial assistance and nutritional support. Esophageal cancer management requires dietary modifications toward soft, nutrient-dense foods that are often more expensive than traditional staples. Additionally, nutritional supplements recommended by healthcare providers prove cost-prohibitive for many patients.

Respondent 10 explained:

"Financial assistance is key to those with esophageal cancer because we are required to eat certain foods, which tend to be more expensive than regular food. Financial assistance and groceries would go a long way in assuring the healing process goes smoothly."

Current social grant systems in South Africa, while providing some financial relief, prove insufficient to meet the comprehensive needs of cancer patients. Participants recommended developing cancer-specific financial assistance programmes to cover transportation, nutritional supplements, and household expenses during treatment periods when employment becomes impossible.

Additionally, participants suggested establishing nutritional support programmes that provide appropriate foods and supplements to esophageal cancer patients. Such interventions could improve treatment tolerance, reduce complications, enhance quality of life, and alleviate financial strain on families.

Discussion

This phenomenological study provides in-depth insights into the lived experiences of patients with esophageal cancer in rural Eastern Cape communities. Findings illuminate the complex interplay between disease symptomatology, healthcare access barriers, cultural health beliefs, and socioeconomic constraints in shaping patient experiences and outcomes. Results align with and extend existing literature while identifying critical gaps in current healthcare delivery systems.

The pattern of delayed help-seeking despite severe symptoms observed in this study resonates with findings from other African contexts. Research in Ethiopia similarly documented prolonged delays between symptom onset and cancer diagnosis, with patients navigating multiple healthcare providers and traditional healers before reaching specialized cancer treatment centres (Asefa et al., 2025). These delays contribute to late-stage presentation and poor prognosis, as esophageal cancer detected at advanced stages carries significantly reduced survival prospects.

Application of the Health Belief Model illuminates factors underlying delayed help-seeking. Perceived barriers—including geographic distance to healthcare facilities, fear of diagnosis, financial constraints, and cultural preferences for traditional healing—substantially outweighed perceived benefits of early medical consultation for many participants. Insufficient awareness of esophageal cancer symptoms as medical emergencies reduced perceived susceptibility and severity, further delaying care initiation.

The reliance on traditional healing systems documented in this study reflects medical pluralism characterising health-seeking behaviours in many African contexts. Rather than representing opposition to biomedical care, traditional healing consultation often serves as a culturally congruent first-line response to illness, particularly for conditions perceived as having spiritual or social etiologies (Zhang,et.al 2025). However, when serious conditions like cancer are attributed to non-biomedical causes, this cultural practice can inadvertently delay life-saving interventions.

Healthcare systems must acknowledge and address this reality through culturally sensitive approaches that respect traditional healing practices while promoting timely access to evidence-based cancer care. Collaborative relationships between biomedical and traditional healthcare providers, combined with community education distinguishing conditions amenable to traditional versus biomedical treatment, may help reduce dangerous delays.

The treatment experiences described by participants align with documented side effect profiles for chemotherapy and radiation therapy in esophageal cancer management. Research consistently demonstrates that multimodal treatment regimens, while improving survival outcomes, impose substantial toxicity burdens including myelosuppression, mucositis, fatigue, and radiation-induced esophagitis (Abana et al., 2023). These treatment-related complications significantly impact quality of life and may compromise treatment adherence, particularly in resource-constrained settings with limited supportive care infrastructure.

Participants' resilience and treatment adherence despite severe side effects reflect adaptive coping mechanisms consistent with the Health Promotion Model. Family support emerged as the most significant protective factor enabling treatment completion. This finding emphasises the critical role of social support systems in cancer survivorship and suggests that family-centred care approaches may optimize treatment outcomes in these contexts.

Geographic barriers to oncology services constitute a structural determinant of health inequity requiring urgent policy attention. The centralisation of cancer treatment services in tertiary urban hospitals, while necessary for technical and economic reasons, creates profound access barriers for rural populations. International evidence demonstrates that distance to cancer treatment facilities negatively impacts treatment initiation, adherence, and survival outcomes (McPhail et al., 2022).

Potential solutions include decentralising certain cancer services to district hospitals, deploying mobile chemotherapy units to rural areas, providing patient transportation assistance programmes, and offering telemedicine consultations, thereby reducing unnecessary travel. South Africa's National Health Insurance reforms present opportunities to address these geographic inequities through intentional service distribution planning, prioritising underserved populations.

The prominence of family support in participants' narratives reflects collectivist cultural values emphasising kinship obligations and mutual care. While this represents a valuable cultural resource, it simultaneously places substantial burdens on family caregivers who often lack formal support or recognition. Caregiver burden in cancer contexts encompasses physical, emotional, financial, and social dimensions, potentially leading to caregiver burnout, depression, and health decline (Zhang et al., 2023).

Healthcare systems must implement interventions supporting both patients and family caregivers. Recommendations include caregiver training and education programmes, respite care services, psychosocial counselling, peer support groups, and financial assistance for caregiving-related expenses. Such comprehensive support systems could reduce caregiver burden while maintaining the benefits of family-centred care.

The financial hardship documented in this study reflects broader challenges facing cancer patients in low- and middle-income countries. Cancer diagnosis often precipitates catastrophic health expenditures—defined as healthcare costs exceeding 40% of household capacity to pay—pushing families into poverty (Zhang et al., 2025). In South Africa's context, where public healthcare is theoretically free at the point of service, hidden costs, including transportation, lost income, nutritional requirements, and non-covered medications, create substantial financial barriers.

Addressing financial toxicity requires multi-pronged interventions: expanded social protection systems providing adequate cancer-specific grants; transportation voucher programmes; nutritional support initiatives; and advocacy for comprehensive essential medicines lists that ensure the availability of all necessary cancer medications in public facilities. These interventions align with universal health coverage principles, emphasising financial risk protection alongside service access.

Finally, participants' emphasis on inadequate health education highlights a critical prevention opportunity. Public awareness campaigns promoting recognition of esophageal cancer symptoms could facilitate earlier diagnosis and treatment initiation, potentially improving survival outcomes. Education initiatives should extend beyond symptom awareness to address modifiable risk factors, including tobacco smoking, alcohol consumption, and dietary practices, aligning with primary prevention strategies.

Limitations

This study possesses several limitations warranting consideration. The relatively small sample size (n=12), while appropriate for phenomenological research, limits generalizability to broader esophageal cancer patient populations. Findings reflect the experiences of patients who successfully accessed treatment at tertiary facilities; the experiences of individuals unable to access care remain unrepresented.

The cross-sectional design captures experiences at a single time point, potentially missing longitudinal changes in perspectives and needs throughout the cancer trajectory. Prospective longitudinal studies following patients from diagnosis through survivorship or end-of-life care would provide a richer understanding of evolving experiences.

Language barriers may have influenced data quality, as some interviews required translation between isiXhosa and English. While efforts were made to ensure translation fidelity, subtle meanings and cultural nuances may have been lost.

Finally, the study focused exclusively on patient perspectives, excluding healthcare providers, family caregivers, and traditional healers whose insights would provide additional contextual understanding. Future research should adopt a multi-stakeholder approach that encompasses diverse perspectives on esophageal cancer care in these communities.

Conclusions

This phenomenological study illuminates the multifaceted challenges confronting esophageal cancer patients in rural Eastern Cape communities. Findings emphasise the complex interplay between disease characteristics, healthcare system factors, socioeconomic constraints, and cultural health beliefs in shaping patient experiences and outcomes. Based on these findings, several recommendations emerge for healthcare providers, policymakers, and researchers:

Implement comprehensive community-based health education campaigns promoting esophageal cancer awareness, symptom recognition, and the importance of early medical evaluation. Education initiatives should leverage multiple channels, including community health workers, radio broadcasts, engagement with traditional leaders, and school-based programmes. Develop collaborative frameworks between biomedical and traditional healthcare systems that foster mutual respect and communication and ensure patients have timely access to evidence-based cancer care. Address geographic barriers through service decentralisation, mobile chemotherapy units, patient transportation assistance programmes, and telemedicine consultations to reduce unnecessary travel. Establish comprehensive support systems that address patient and family caregiver needs, including psychosocial counselling, peer support groups, caregiver training, respite care, and financial assistance programmes. Develop cancer-specific financial protection mechanisms, such as enhanced social grants, transportation vouchers, and nutritional support programmes, to address the economic burden of cancer care. Enhance palliative and supportive care services across the cancer care continuum by integrating symptom management, nutritional support, pain control, and quality of life optimization. Conduct further research on long-term survivorship experiences, healthcare provider perspectives, traditional healer roles in cancer care, and the effectiveness of interventions to improve outcomes in this population.

Implementation of these recommendations requires coordinated efforts across government health departments, non-governmental organisations, community leaders, and healthcare providers. By centering patient experiences and needs in policy and programme development, South Africa can reduce esophageal cancer morbidity and mortality while improving quality of life for affected individuals and families in high-burden communities.

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